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Thank you for inviting me to speak today on the topic, "Who's Looking Out for Special Needs?"

I especially want to thank my friend Elizabeth Davis, who was so instrumental in making sure that the issues facing the disability community have played a prominent role in this conference. As you may know, there have been several break-out sessions addressing this topic, and I hope to build on the great information shared there.

On behalf of Secretary Chertoff, and my colleagues George Foresman and Chief David Paulison, with whom we have worked closely on these issues, I want to look back at Katrina and Rita, which will help us identify the main issues involved in this complex area. Then, I want to look forward and suggest some specific recommendations.

There are 3 messages I want to leave you with today:

First, the needs and talents of people with disabilities must be more effectively integrated throughout the emergency management process. While all Americans face difficulties during emergencies, these difficulties are often compounded for people with disabilities and their families. This is not a "niche" issue, worthy of a footnote or two as we discuss the lessons learned from Katrina. As I will demonstrate later, the disability community constituted approximately 20% of the people who lived in the Gulf Coast region. These are complex issues, affecting a large number of people, and we must do a more effective job in addressing them.

Second, we recognize that state and local governments are the primary first responders in a disaster. Disasters, by their very nature, occur locally – in communities far removed from federal assets. State and local responders are the first on the scene and are most attuned to the needs and concerns of local populations. As the chair of the federal Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities, we recognize that our role and responsibility is not to add new burdens to your work, but to identify ways that we can help you effectively deal with the complex and unique issues in this arena. And I hope to explain some of those today.

And finally, people with disabilities do not want to be passive consumers of help. Rather, people with disabilities have a tremendous amount to offer because they bring a unique blend of energy, experience, ideas and determination to these issues. People with disabilities, their families and the organizations that serve them want to help; all you have to do is enlist them in the service.

[Slide 2]. Let me give you a little background first. I am the chair of the Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities. Our Council was created by President Bush's Executive Order in July 2004, and so we had been operating for just over a year when Katrina hit. We have divided our work into 8 key areas -- for example, we have a group

working on how to evacuate people with disabilities from workplaces; we have a group working on transportation issues that people with disabilities face in times of emergencies; and, we have a group working on communications issues that people with disabilities face in times of emergencies.

We had produced two important reports, held a major conference, and launched a new website with resources in these areas.

When Katrina hit, we began to receive urgent emails and telephone calls -- all day every day for several weeks. Let me take a few minutes to identify for you the major issues that the disability community in the Gulf Coast region faced.

[Slide 3]: The availability of durable medical equipment was a major issue. As you can see from this photograph, this man is slumped in the heat on a traffic overpass. This man clearly is not sitting in his own wheelchair. He is sitting in a wheelchair that someone found in an ambulance or at a hospital emergency room. He probably could not get out of the rushing water in his customized wheelchair. This generic wheelchair does not have proper support, which a customized one would. Generic wheelchairs like this can cause terrible sores that can require surgery and can actually be life-threatening. We had dozens of calls on this point - wheelchairs, hearing aids, crutches, walkers and so many other kinds of equipment had been lost in the evacuation. For example, at the New Orleans airport, there were dozens of expensive, customized wheelchairs that had been left. In the chaos of that evacuation, people had been pulled out of the wheelchairs and placed quickly onto the next available airplane.

As a federal Council, we were able to make a dent on some of these issues. For example, we were able to facilitate the delivery of two truckloads of durable medical equipment that several disability advocacy organizations had accumulated. We were also able to help recover many of the wheelchairs at the New Orleans airport.

[Slide 4]: We received calls about senior citizens in distress in the days after the hurricanes. We received urgent emails and calls about people who needed oxygen, but their oxygen supplies were running low. Of course, we all remember the terrible scene when a bus load of senior citizens were being transported, and the oxygen had not been properly and safely transported ... and the bus exploded into flames on a highway, incinerating many of the people on that bus. We all remember the indictment of the operators of a nursing home, on thirty-some counts of negligent homicide.

[Slide 5]: We received calls and emails about people with disabilities who could not be easily or properly evacuated. Here you see a Texas game warden carrying prosthetic legs through the rising water.

[Slide 6]: Here you see a rescuer carrying a young man who is unable to walk. Unfortunately, some of the stories about evacuation problems were quite horrific. One of our colleagues who leads a national disability organization in Washington was on the telephone with the care provider for a woman who uses a wheelchair in New Orleans. They were talking on the cell phone as the water crept higher and higher in the house, and as she vainly tried to get the woman out of the wheelchair

and up the stairs to higher ground. Eventually, she had to rush to safe higher areas in house, but the woman in the wheelchair was lost in the flood.

[Slide 7]: Let me give you some important data on evacuation issues. The Kaiser Family Foundation took a poll of people from New Orleans who were evacuated to the Astrodome, asking: “Which of these was the biggest reason you did not leave?”

22% of the respondents said, “I was physically unable to leave.” In addition, 23% said, “I had to care for someone who was unable to leave.” I am not a whiz at mathematics, which is why I am a lawyer and not a doctor, but it seems to me that if you add up those two numbers – you get 45% of the people who had to be evacuated from New Orleans were connected to disability.

[Slide 8]: We received phone calls and emails about people desperately needing medications. People had to evacuate without adequate supplies of insulin, heart medicines, drugs for epilepsy, medicines to control various mental illnesses, and so on. Here you see a man in a wheelchair waiting for a local pharmacy to open its doors, and a national guardsman also at the door.

We received calls about pharmacies in Texas and Alabama and other states not accepting Medicaid cards from Louisiana. We have on our federal Council a senior representative from the Department of Health and Human Services. She was able to go to the leadership of the Medicaid program, who issued immediate guidance advising pharmacies that Medicaid would reimburse for expenses from out-of-state cards.

[Slide 9]: As the days passed, we began to receive calls about the shelters not being prepared for the disability community. The National Organization on Disability sent a team to the area in the weeks after Katrina to survey the shelters. Their work documented the problem, and I encourage you to read their report at [www.nod.org](http://www.nod.org).

Here is a photograph from the Astrodome. At least they recognized that there were deaf people in the stadium. But the National Organization on Disability report found the following:

- Less than 30% of shelters had access to American Sign Language interpreters
- 80% did not have TTYs (that is, teletypewriters)
- 60% did not have TVs with open caption capability
- Only 56% had areas where oral announcements were posted.
- NOD concluded: “This meant that the deaf or hard of hearing had no access to the vital flow of information.”

(Report on SNAKE Project, Oct. 2005)

Our Council is working with leaders of the American Red Cross to improve the performance of shelters with regard to people with disabilities. You heard earlier this week about new efforts to improve the Red Cross’ work, and you can also expect to see improvements with regard to the disability issues.

[Slide 10]: The despair of this tragedy brought out the best in many Americans, and that included the disability community around the country. We received many offers of help. For example, we received an email from someone who ran a camp in a rural area that had been unaffected by the hurricanes. The person said that the camp was set up to receive 350 kids with autism -- there was food, supplies, bedding and the appropriate facilities. All they wanted was for the authorities to let families with autistic children know that they could come and live there.

This illustrates the point that people with disabilities do not want to be passive consumers of help. Exactly the opposite. People with disabilities want to be respected as individuals who have something positive to contribute. They simply want to be given the opportunity to assist you with their expertise and experience.

[Slide 11]: Eventually, accessible housing became the largest issue we faced. We began to deal with the fact that the mobile homes were not accessible -- that is, a person in a wheelchair could not get into the front door! And once there, he or she could not reach the cabinets, could not reach the faucets, and could not get into the bathroom or the bedrooms.

We sent an expert on disability issues to serve on Admiral Allen's staff in Baton Rouge, and another to serve on Admiral Hereth's staff in Austin. In Baton Rouge, our expert was able to bring in an architect who specializes in accessibility issues, who helped look at the specs for the manufactured homes being provided, and at the sites for the new temporary communities being built. As a result of that work, we were able to retrofit some mobile homes -- here you see a crew of men building a ramp up into a mobile home.

One other point about housing: Hundreds and probably thousands of people with disabilities were evacuated to nursing homes. We do not want people to stay in these institutionalized settings, but instead to be able to return to their homes, their communities, their churches, their jobs, their friends. It is expensive to us as a country to have people who could live on their own, in their own home and in their own community, instead living in a costly nursing home. But more importantly, it is a violation of basic principles of human freedom for people who want to live on their own, independently, to be forced to live in institutional settings.

Why was this happening in such large numbers? Surely nothing like this had been seen before - why here?

Actually, as we did our research, all that you have just seen was simply repeating what was seen on smaller scales in many other disasters. We discovered a report written after 9/11 with many of the same conclusions. We discovered a report written after the California wildfires with many of the same conclusions. We even discovered a report written after Hurricane Andrew with many of the same conclusions. It is time now to stop writing reports cataloguing the problems, but instead to take action to implement common-sense ideas for improvements.

Let me show you some demographic information that will hopefully be illuminating.

[Slide 12]: This slide shows that almost 250,000 of the residents of the New Orleans metropolitan area described themselves as “disabled” in the 2000 Census. According to the Census, 21.3% of the city’s residents were people with disabilities.

[Slide 13]: Let me break that down for you in more detail. According to the 2000 Census, almost 25,000 people stated that they were blind or deaf. Over 100,000 people stated that they had a physical disability that prevented them from walking, climbing stairs, lifting, dressing, bathing or even getting around inside their own home. Almost 65,000 people were categorized as having a “mental disability” – an obscure category which would probably include people with cognitive disabilities as well as some of the few who would self-identify as a person with mental illness.

I hope that this gives you more insight into the size of the disability community in New Orleans.

The size of that community is, unfortunately, not an isolated or unique phenomenon.

[Slide 14:] Let’s look at three random state populations. According to the Census, 13.7% of the population of the State of Oregon has a “sensory, physical, mental or self-care disability.” The numbers are similar in many other states – for example, the state of Washington: 12.9% of the population; the State of Maine: 14.8% of the population.

The size of the disability community does seem to be higher in many urban areas.

[Slide 15:] Here are statistics from a sampling of cities.

- Boston: 213,019 people with disabilities (2000 Census).
- Virginia Beach: 97,457.
- Jacksonville: 250,556.
- Raleigh/Durham/Winston-Salem: 160,000.
- Memphis: 254,005.
- Chicago: 1,084,032.

I hope that you now have a good overview of the major issues that the disability community faces in times of emergency. I also hope that you see that the experiences in the Gulf Coast were not atypical – all states and all large urban areas have a sizable disability community that they must take account of as they undertake preparedness campaigns, and as they plan for response and recovery efforts.

At the beginning, I stressed that our role is not to add burdens to you, but to give you resources to help you do job. I want you to know that we are addressing recommendations for change to all of the players in this complex field:

- For FEMA
- For our Preparedness Directorate
- For our Office, and our partners on the Council

- For the Red Cross; and,
- For the disability community

We all have a great deal of work to do in this area, myself included. Let me offer 4 recommendations that are particularly relevant to state and local emergency managements officials.

[Slide 16:] Recommendation 1: Re-evaluate your response and recovery plans to ensure that the talents and needs of people with disabilities are accounted for. It is critical that the written plans and protocols take account of disability issues. It is extremely important that the plans acknowledge the demographics of the disability community in any particular area, and that they lay out specific steps that will be taken to effectively evacuate these people.

We are working on this on the federal level. As you probably know, President Bush and the Congress directed that the largest state and urban area evacuation plans be reviewed. We are participating in that project, known as the Nationwide Plan Review. We have convened a panel of 10 subject matter experts who spent a week in our offices reading and analyzing plans. We are going to incorporate their analysis into the final report on the plan reviews, which will hope will be extremely useful to you.

[Slide 17:] Recommendation 2: Integrate people with disabilities into the process.

The best way to know how to handle situations involving wheelchairs is to ask someone who uses one. The best way to know how to handle situations involving people who are deaf is to ask someone who is deaf.

Earlier in my legal career, I was asked to investigate a chain of gas stations to see if they were accessible. I do not have a disability. But I traveled with colleagues who used wheelchairs. I could immediately see things I never saw before -- that 2 inch lip in front of the sidewalk into the store; the way the door opened onto the sidewalk, so that people in wheelchairs couldn't possibly get in the store; the height of the cashier's counter; the displays in the aisles that blocked people from moving; and many other things.

You will also see things you have never seen before if you will just take people with disabilities along with you.

Let me suggest a corollary to this recommendation: Look for opportunities to include people with disabilities in your exercises. This may be the easiest way to fully understand the issues. We are also working on this on a federal level – for example, by including disability community organizations in the Top Off 3 exercise, and planning for them in Top Off 4, as well as in other exercises.

The logical question you might ask is: “Who should I contact? I don’t know anything about disability service organizations – where could I find them?” Let me suggest one easy place to start: the National Organization on Disability has created an “Interactive Map of Disability and Emergency Preparedness Resources.” Go to [www.nod.org](http://www.nod.org) and look for this map. All you have to do

is click on your state, and it will give you the contact information for several major disability service organizations. These organizations will lead you to others that are active in your state, county or city. This is a marvelous resource that I encourage you to take advantage of.

[Slide 18:] Recommendation 3: We should hire subject matter experts on these issues to work within our emergency management agencies – to ensure that our efforts are informed by specialists in this complex and unique field. When you have a vacancy, consider hiring a person with a disability to fill it. When you have money to employ an expert, consider bringing in an expert on accessible transportation, for example.

We are also taking this to heart. As I mentioned earlier, Secretary Chertoff ordered me to get subject matter experts to the JFOs in Baton Rouge and Austin. They were able to help their colleagues there to deal with specialized issues, and they worked around the clock for several weeks. On our federal Council, we have many people with disabilities who are informing our work. In my office, I have two incredible people who lead this work.

[Slide 19:] Finally, Recommendation 4: Take advantage of the resources available to you. I have already mentioned the excellent interactive map on the National Organization on Disability's website. Please also take advantage of our Council's "Resource Center": [www.disabilitypreparedness.gov](http://www.disabilitypreparedness.gov). We have accumulated there dozens of important guides, manuals, and reports that have been written by the Red Cross; the Departments of Health and Human Services, Labor and Justice; the Centers for Disease Control; FEMA; and the Center for Universal Design, just to name a few. For example, there is an excellent little guidebook from the American Association for Health and Disability titled, "Tips for First Responders." This wonderful book gives in summary form dozens of ideas for first responders who are unfamiliar in working with senior citizens or people with disabilities. It is the kind of booklet that you could hand out by the dozens to your first responders in your community. And, as I said, this is only one of many of resources available at this website.

I want to conclude where I started: we recognize that state and local governments are the primary first responders in a disaster; and, we recognize that the burdens placed upon you are tremendous. However, we offer you a tremendous resource – people with disabilities, their families and the organizations that serve them desperately want to help you. They want to roll up their sleeves with you and identify solutions that will make the Katrina experience an ancient memory.

Thank you and God bless you as you return to your communities to tackle these complex issues.